PRESENTATION

Keeping Children Active Physical Therapy

SPEAKER

Patty Stott
Elevation Wellness
Arvada, CO (telehealth)

- Patricia Stott, PT, DPT, MS, ATC, CHT, CYT
- Owner Elevation Wellness, Arvada, CO with 95% HSD/EDS population
- Physical Therapy, Functional Medicine, Herbalism
- Co-Author on Book about this topic
- Co-host for EDS ECHO Allied Health Professionals Group, North America
- info@elevationwellness.co
- www.elevationwellness.co

NO CONFLICTS OF INTEREST TO REPORT

Outline

- Presentation of HSD/EDS in Children
- What Can Affect Activity
- What Has Been Investigated
- Recommendations for Activity

Disclaimer: Patient and parent permission has been obtained for all images used in this presentation.

Presentation in the Pediatric Population

Musculoskeletal

- Delayed motor development
- Speech impairments
- Low muscle tone
- Choking incidents or difficulty swallowing
- Sleep apnea
- Clumsy movement patterns
- Growing pains
- Inguinal hernia
- Nursemaid's elbows
- Hip dysplasia
- Difficulty with handwriting

Systemic

- Food intolerances
- Diarrhea and/or constipation
- GI issues
- Skin hyperextensibility
- Poor wound healing
- MCAS symptoms
- Dysautonomia symptoms
- Anxiety symptoms (separation anxiety, social phobia, fear of physical injury)
- Brain fog/difficulty concentrating

Primary Concerns with Activity

- Pain
- Coordination/gait mechanics
- Fatigue
- Instability/injury

POTS Can Impact Activity Tolerance

- POTS can be present in children as well and impact school participation and recreational activity
- Prevalence of POTS (ages 7-18 y/o) found to be 6.8% (600 Chinese individuals, Tao at.al., 2019)
- This can present as decreased ability to participate/initiate activity, or it can be seen as post exertional malaise

POTS Can Impact Activity Tolerance

Children with POTS are more likely to also demonstrate:

- Chronic fatigue syndrome
- Sleep disorders
- Migraines
- Irritable bowel syndrome or functional dyspepsia
- Ehlers-Danlos Syndrome

These issues make exercise more challenging!

(Zhang et.al., 2020)

MCAS in Children

- MCAS is present in children as well!
- MCAS can be limiting to activity for a number of reasons as well:
  - Exercise intolerance
  - Joint pain
  - Nerve mediated back pain and sciatica (tethered cord?)
  - Appearance of EIA
  - Reactions to sweat or friction of materials (uniforms, undergarments, equipment, etc)

Risk of Injury in Sport with Hypermobility

- Current research does not show a link between the risk of acute injury and hypermobility in athletic populations
  - However, poor motor control may be a risk for people who are hypermobile
- One exception- possible increased risk for ACL injury to the knee, but minimal research has been performed
- No research on the severity of injury or recovery outcomes in individuals with a history of HSD/EDS
- Many individuals with HSD/EDS do feel more prone to injury
- Some individuals demonstrate complications and delay in healing from an injury, and this may be related to additional comorbidities affecting the body's healing process

(Blokland, 2017; Bukva, 2019; Oddy, 2017; Sundemo, 2019)

Children and Exercise Programs

- 6 week generalized program and a joint specific strengthening program both showed similar significant improvements in pain reports for patients with hypermobility (Kemp, 2010)
- Possible improvement in self esteem when strengthening into endranges of hypermobile motion (Pacey et.al., 2013)
- Orthotics may be helpful in improving gait mechanics
- Somatosensory orthoses (orthotics and compression garments) may help regulate somatosensory input and improve postural stability (DuPuy, et.al., 2017)

Social Considerations for Youth

- Poor health/chronic conditions can increase the rate of anxiety and depression
- Chronic medical conditions (POTS) can lead to decreased school attendance, lack of social participation, underachievement, and frequent medical visits

*Encouraging normalcy and tolerated participation can improve quality of life and condition symptoms

*If possible, connect kids and families to support groups locally or online (chronic illness, specific EDS support groups, etc.)

(Zhang, 2020; Kizilbash, 2014)

Roadblocks for Children in Exercise Participation

1. Pain
2. POTS and/or fatigue
3. Kids don’t like the exercises
4. Fear
5. Impaired balance, proprioception, coordination
6. Depression
7. Deconditioning
8. Anxiety around social environments
9. Lack of parental involvement
10. Time/focus on other medical issues
11. Lack of dedicated exercise time in a day (structure)
12. Lack of understanding the benefit of the treatment or intervention

Recommendations for Roadblocks

1. Pain management
2. POTS & fatigue management, sleep hygiene, nutritional evaluation for deficiencies
3. Find activities they enjoy
4. Trust, pain management, slow progression
5. Activity focus integrating balance, proprioception, coordination; compression garments
6. Focus on positive outcomes; recommend kid support group
7. Gradual exercise progression
8. Anxiety specific interventions or social support in situations
9. Educate parents, adapt family routines
10. Recognize that PT might not be most important focus at this time

Sports Recommendations with Pediatrics

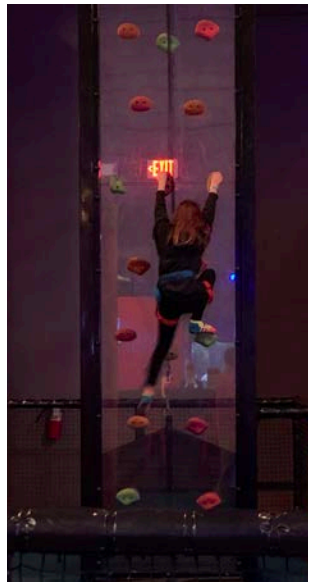
- Based on the individual presentation
- Encourage healthy movement and activity for the individual
- Consider a sport specific evaluation to determine if a sport or activity is possible (i.e. evaluate the appropriate joints and muscles primarily needed for a swimmer to perform specific strokes)
- May need to be taught pain education or self check-ins to be sure they are not over-doing an activity or sport
- High impact/high risk catastrophic sports might not be tolerated by some children with HSD/EDS; this is on an individual basis; safety first

Exercise/Movement Strategies

- Intentional movement based sports and activity (focus on proprioception and body control)
- Teach joint position (avoid hyperextension), if able to, at a younger age
- Hand dexterity and strengthening exercise through play, games, and weight bearing if tolerated
- Avoid individually aggravating sports (i.e. wrestling if the child is unable to control shoulder subluxations)
- Physical exercise is encouraged for children with POTS to enhance the muscle pumping action and improve autonomic tone (aerobic and strengthening combined)
- Core strengthening based play
- Compression clothing, orthotics if needed

(Kizilbash et.al., 2014; DuPuy, et.al., 2017)

Mind-Body Sports



- Martial Arts
- Dance
- Yoga
- Ninja Classes
- Parkour
- Swimming
- Cross Country/Track and Field
- Rowing
- Rock Climbing
- Weight Lifting
- Cycling
- Fencing
- Diving
- Figure Skating
- Gymnastics

Sports with less reactivity and more intentional individual movement. The individual does not have to worry about the actions of another person or object.

In-School Support for Energy Conservation

HSD/EDS

- Modified seating for comfort
- Modified writing utensils
- Frequent breaks for energy management
- Breaking up assignments into smaller tasks
- Extra time on assignments
- Link for EDS school accommodations: https://ehlers-danlos.com/wp-content/uploads/Educator-Parent-Guide-2016.pdf

Dysautonomia

- Modified seating options for concentration (therapy balls, exercise pedals)
- Therabands attached to chair legs
- Horizontal breaks as needed throughout the day
- Accessible water bottle and electrolytes at the desk
- Ability to use the restroom during class as needed
- Time and a half permitted for test taking
- Link for POTS school accommodations: http://www.dysautonomiainternational.org/page.php?ID=107

References

1. Aich A, Afrin LB, Gupta K. Mast Cell-Mediated Mechanisms of Nociception. Int J Mol Sci. 2015 Dec 4;16(12):29069-92. doi: 10.3390/ijms161226151. PMID: 26690128; PMCID: PMC4691098.
2. Aubry-Rozier B, Schwitzguebel A, Valerio F, et al. Are patients with hypermobile Ehlers-Danlos syndrome or hypermobility spectrum disorder so different? *Rheumatol Int*. Oct 2021;41(10):1785-1794. doi:10.1007/s00296-021-04968-3
3. Blokland D, Thijs KM, Backx FJ, Goedhart EA, Huisstede BM. No Effect of Generalized Joint Hypermobility on Injury Risk in Elite Female Soccer Players: A Prospective Cohort Study. Am J Sports Med. 2017 Feb;45(2):286-293. doi: 10.1177/0363546516676051. Epub 2016 Dec 14. PMID: 28146401.
4. Bovet C, Carlson M, Taylor M. Quality of life, unmet needs, and iatrogenic injuries in rehabilitation of patients with Ehlers-Danlos Syndrome hypermobility type/Joint Hypermobility Syndrome. *Am J Med Genet A*. Aug 2016;170(8):2044-51. doi:10.1002/ajmg.a.37774
5. Bukva B, Vrgoč G, Madić DM, Sporiš G, Trajković N. Correlation between hypermobility score and injury rate in artistic gymnastics. J Sports Med Phys Fitness. 2019 Feb;59(2):330-334. doi: 10.23736/S0022-4707.18.08133-1. Epub 2018 Jan 10. PMID: 29327826.
6. Chen G, Du J, Jin H, Huang Y. Postural Tachycardia Syndrome in Children and Adolescents: Pathophysiology and Clinical Management. *Front Pediatr*. 2020;8:474. doi:10.3389/fped.2020.00474

References

1. Dupuy EG, Leconte P, Vlamynck E, Sultan A, Chesneau C, Denise P, Besnard S, Bienvenu B, Decker LM. Ehlers-Danlos Syndrome, Hypermobility Type: Impact of Somatosensory Orthoses on Postural Control (A Pilot Study). Front Hum Neurosci. 2017 Jun 8;11:283. doi: 10.3389/fnhum.2017.00283. PMID: 28642694; PMCID: PMC5462950.
2. Engelbert RHH, Juul-Kristensen B, Pacey V, et al. The Evidence-based rationale for physical therapy treatment of children, adolescents and adults diagnosed with joint hypermobility syndrome/hypermobile Ehlers Danlos Syndrome. *Am J Med Genet C Semin Med Genet*. Mar 2017;175(1):158-167. doi:10.1002/ajmg.c.31545
3. Kizilbash SJ, Ahrens SP, Bruce BK, et al. Adolescent fatigue, POTS, and recovery: a guide for clinicians. *Curr Probl Pediatr Adolesc Health Care*. May-Jun 2014;44(5):108-33. doi:10.1016/j.cppeds.2013.12.014
4. Oddy C, Johnson MI, Jones G. The effect of generalised joint hypermobility on rate, risk and frequency of injury in male university-level rugby league players: a prospective cohort study. *BMJ Open Sport Exerc Med*. 2016;2(1):e000177. doi:10.1136/bmjsem-2016-000177
5. Pacey, V., Tofts, L., Adams, R.D. *et al.* Exercise in children with joint hypermobility syndrome and knee pain: a randomised controlled trial comparing exercise into hypermobile versus neutral knee extension. *Pediatr Rheumatol* **11,** 30 (2013). https://doi.org/10.1186/1546-0096-11-30
6. Russek LN, Stott P, Simmonds J. Recognizing and Effectively Managing Hypermobility-Related Conditions. *Phys Ther*. Sep 1 2019;99(9):1189-1200. doi:10.1093/ptj/pzz078

References

1. Simmonds JV, Herbland A, Hakim A, et al. Exercise beliefs and behaviours of individuals with Joint Hypermobility syndrome/Ehlers-Danlos syndrome - hypermobility type. *Disabil Rehabil*. Feb 2019;41(4):445-455. doi:10.1080/09638288.2017.1398278
2. Smith TO, Jerman E, Easton V, et al. Do people with benign joint hypermobility syndrome (BJHS) have reduced joint proprioception? A systematic review and meta-analysis. *Rheumatol Int*. Nov 2013;33(11):2709-16. doi:10.1007/s00296-013-2790-4
3. Song B, Yeh P, Nguyen D, Ikpeama U, Epstein M, Harrell J. Ehlers-Danlos Syndrome: An Analysis of the Current Treatment Options. *Pain Physician*. Jul 2020;23(4):429-438.
4. Tao C, Lu W, Lin J, Li H, Li X, Tang C, Du J, Jin H. Long-Term Outcomes of Children and Adolescents With Postural Tachycardia Syndrome After Conventional Treatment. Front Pediatr. 2019 Jun 27;7:261. doi: 10.3389/fped.2019.00261. PMID: 31316954; PMCID: PMC6610301.
5. Zhang Q, Xu B, Du J. Update of Individualized Treatment Strategies for Postural Orthostatic Tachycardia Syndrome in Children. *Front Neurol*. 2020;11:525. doi:10.3389/fneur.2020.00525

Conclusions

- Children with HSD/EDS may carry some qualities that make participation in activity more difficult than with the general population.
- Children with HSD/EDS may be impacted by additional comorbidities that impact activity tolerance as well.
- Activity participation is based on an individual basis of what the child is interested in and what their body may be capable of.
- Finding a consistent (or rotating) activity that incorporates balance, body control, and strengthening to keep up long term is highly recommended.
- Find team members that may be able to help assist with some roadblocks that may come up over time.

Thank you for listening